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REPORT



U. S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE • PUBLIC HEALTH SERVICE

REPORT

***Surgeon General's
Workshop
on Prevention
of Disability from
Arthritis***

*U.S. DEPARTMENT OF
HEALTH, EDUCATION, AND WELFARE
Public Health Service
Division of Chronic Diseases
Diabetes and Arthritis Program
Washington, D.C. 20201*

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Background of the Conference

The need for a national conference on the prevention of disability from arthritis was first described in a long-range planning document that was prepared in the fall of 1963 by the staff of the Diabetes and Arthritis Program, Division of Chronic Diseases, U. S. Public Health Service (PHS). The document noted that, although arthritis is a major public health problem, the dimensions of the problem are not widely recognized. And it stressed that, although therapeutic measures for dealing with the problem are far from ideal, procedures that diminish disability, particularly when applied in a timely fashion, have been devised and should be made available to the millions of Americans who suffer from disabling arthritis.

In June 1964, representatives of the Arthritis and Rheumatism Foundation (now, The Arthritis Foundation), the National Foundation, the American Rheumatism Association, the National Institute of Arthritis and Metabolic Diseases (PHS), and the Diabetes and Arthritis Program (PHS) met in San Francisco to give further consideration to the need for a national conference on arth-

ritis. At the conclusion of this meeting, it was the consensus of the group that such a conference was vitally needed. Participants submitted a recommendation to this effect to the Surgeon General and offered to serve as a steering committee to plan the conference. On the basis of this recommendation, the Surgeon General agreed that a conference should be held and accepted the participants' offer to serve as a Steering Committee. This Committee, later enlarged, met several times during 1964.

In these subsequent meetings, the Steering Committee determined that the emphasis of the deliberations should be on community health services, as opposed to basic research. Therefore, the title of the Conference, **THE SURGEON GENERAL'S WORKSHOP ON PREVENTION OF DISABILITY FROM ARTHRITIS**, reflected this emphasis on prevention. The Steering Committee also determined that the objectives of the conference should be to:

1. Assess the problem
2. Assess the resources to meet the problem
3. Determine gaps between needs and resources
4. Recommend action to close the gaps

The Workshop was held May 5-8, 1965, at Airlie House, Warrenton, Virginia. About 100 persons participated. Represented were every health profession, medical economics, science writing, health and medical insurance, and other specialties. To accomplish intensive discussion, the total group was divided into seven Workshops:

1. Public Education and Information
2. Diagnosis and Treatment Facilities
3. Long-Term Control and Management
4. Professional Education
5. Clinical Investigation and Training
6. Voluntary and Public Agency Activities and Programs
7. Socioeconomic Aspects (Financial Resources)

Each Workshop reported back to the total group and each report was discussed by the total group.

This report is a summary of the Workshop reports. Although it represents a consensus of the total group, no individual participant or agency is necessarily in agreement with the total report; and it should not be inferred that any individual participant identifies himself with the report.



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WORKSHOP 3

Currier McEwen, M.D., Chairman

WORKSHOP 4

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WORKSHOP 5

John L. Decker, M.D., Chairman

WORKSHOP 6

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WORKSHOP 7

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The Problem of Preventing Disability from Arthritis

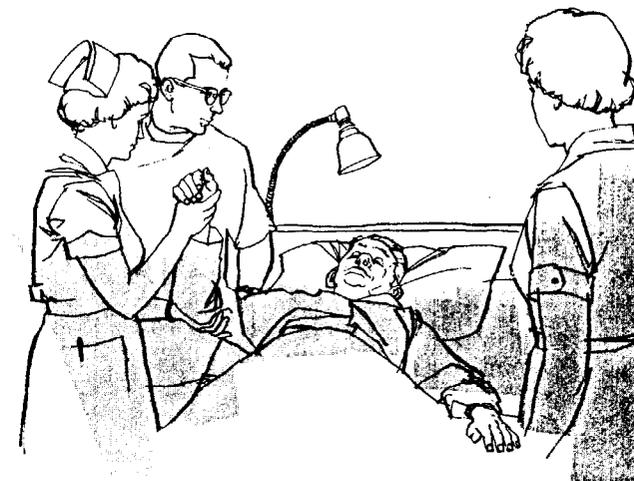
The crippling effect of arthritis on the citizens of this country has created an economic and sociologic problem that can no longer be ignored. Arthritis is the number onecripler in the United States. And the National Center for Health Statistics (PHS) recently reported that arthritis ranks second only to heart disease as the leading cause of limitation of activity for persons who suffer from chronic disability.

The physical ravages of arthritis impose great economic and social burdens on all members of society. Arthritis gradually withdraws from productive activity large numbers of otherwise capable people. The latest estimate of the number of persons in the United States who report that they have arthritis or rheumatism is now 12,668,000.

A more dramatic indication of the physical waste from arthritis appears in data that show that 3,300,000 arthritics in this country maintain, during home interview, that they suffer limitation of activity because of arthritis. About 700,000 report that they are unable to work, keep house, go to school or engage in most recreational activities (see Table A, page 10).

Economic Problem. The total cost of arthritis to the public has not been determined. That it is substantial is indicated, in part, by a 1962-63 survey of recipients of public assistance under the program of aid to the permanently and totally disabled. Of the more than 500,000 persons who were receiving aid under this program, an estimated 33,000, or 6.6 percent, had arthritis as their primary impairment. At least 17,000 additional recipients had arthritis as their secondary impairment, for a total of 50,000 recipients with primary or secondary impairment. Since the average payment in this program is approximately \$78.00 per month, or \$948 per year, a total of \$47 million was paid annually to the 50,000 recipients.

To compound this economic tragedy, arthritis accounts for over 12 million work-



loss days per year. In terms of productivity, the loss to the economy is estimated to be \$520 million a year.

Loss of earning power, coupled with the

Table A Number and percent distribution of persons with arthritis or rheumatism, by type of usual activity status, and by degree of activity limitation, United States, July 1961-June 1963. (civilian noninstitutional population)

Type of usual activity and degree of activity limitation	Number persons (in thousands)	Percent distribution
Total	12,668	100.0
Usual activity status:		
Preschool or school age	57	0.4
Working	4,078	32.2
Keeping house	5,926	46.8
Retired	1,991	15.7
Other or unknown	615	4.9
Degree of activity limitation due to arthritis:		
Limited, total	3,300	26.0
Unable to carry on major activity	697	5.5
Limited in major activity	1,888	14.9
Not limited in major activity, but otherwise limited	714	5.6
None, total	9,368	74.0

¹ Refers to ability to work, keep house, or engage in school or pre-school activities. Note: Does not include persons in nursing homes.

Source: Unpublished data, and Chronic conditions and activity limitation, United States, July 1961-June 1963. Estimated annual average. U. S. Department of Health, Education, and Welfare, Public Health Service Publication No. 1000-Series 10, No. 17, May 1965. Washington: U. S. Government Printing Office.

high costs of treatment and care, often leads the victim of arthritis to economic dependence upon other members of the family or upon community agencies. This

Table B Estimated annual work productivity losses, benefit payments, and expenditures due to arthritis.

	Total	\$1,297,000,000
Work productivity loss, total		\$ 520,000,000
Among arthritics who work, but lose time because of the arthritis	\$220,000,000	
Among arthritics who are unable to work and who receive disability benefits (minimal)	\$300,000,000	
Benefit payments to arthritics, total (minimal)	\$ 132,000,000	
From Old-Age, Survivors, and Disability Insurance, Social Security Administration	\$ 85,000,000	
From Aid to the Permanently and Totally Disabled, Welfare Administration	\$ 47,000,000	
Nonprescription drugs (except aspirin)	\$ 435,000,000	
Physicians' visits	\$ 150,000,000	
Hospitalization	\$ 60,000,000	
Other:		
Prescription drugs	?	
Aspirin	?	
Physical therapy	?	
Certain services in doctors' offices	?	
Nursing home care	?	
Care in private homes	?	
Private insurance benefits	?	
Federal, State, and local income taxes lost	?	

costs the public money. Although the true figure is not known, arthritis is estimated to cost the U.S. economy over a billion dollars a year. Not counted in this figure

Table C Number of persons per 1,000 civilian non-institutional population with activity limitation due to arthritis or rheumatism, by family income and age, United States, July 1961-June 1963.

Annual family income and age	Total population (in thousands)	Persons with activity limitation due to arthritis or rheumatism	
		Number (in thousands)	Per 1,000 population
Total	181,964	3,300	18.1
Under 45 years	128,658	327	2.5
45 years and over	53,306	2,973	55.8
Under \$4,000	56,390	2,033	36.1
Under 45 years	34,897	114	3.3
45 years and over	21,493	1,919	89.3
\$4,000 and over	115,056	1,083	9.4
Under 45 years	87,299	200	2.3
45 years and over	27,757	883	31.8
Income unknown	10,518	184	17.5
Under 45 years	6,463	13	2.0
45 years and over	4,055	171	42.2

Source: Chronic conditions and activity limitations, United States, July 1961-June 1963. Estimated annual average. U. S. Department of Health, Education, and Welfare, Public Health Service Publication No. 1000-Series 10, No. 17, May 1965. Washington: U. S. Government Printing Office.

are the costs of prescription drugs, aspirin, certain services in doctor's offices, nursing home care, care in private homes, private insurance benefits, and Federal, State, and local income tax losses (see Table B, page 10).

Of the \$435 million that is spent annually for medications for arthritis, \$250 million is wasted by arthritics on products that are falsely advertised or grossly misrepresented. Frequently, quackery flourishes because the physician who first sees the arthritis patient is not trained to cope adequately with the problem. In addition, public and private organizations do not have the resources to counter the promotion of fraudulent remedies. In lieu of concrete information about arthritis, the sufferer, believing that nothing can be done, wanders aimlessly into the pit of quackery. When he does seek the aid of a knowledgeable physician, his disease may have progressed beyond the point at which effective measures might have been applied.

Growing Problem. Since arthritis lacks the virulence to kill, prevalence rises with age. Victims of arthritis may become crippled, disabled, and wracked with pain, but they continue to live.

Arthritis has its greatest impact on the lower income groups. As family income goes down, the percentage of arthritis and, the percentage of arthritics in the disabled group, goes up.

A comparison of persons with limitation of activity by family income and age indicates that arthritics who are over 45 years of age with family incomes *under* \$4,000 have even more limitation of activity than those who are over 45 years of age with incomes *over* \$4,000 (see Table C, page 10). It can be said that arthritis is associated with lower income, regardless of age, although it is also associated with increasing age.

Psychological and Sociological Impact. While our society manifests a strong consciousness of responsibility for the handicapped and disabled, it nevertheless places emphasis on youth, activity, and achievement—values that are hardly compatible with a long-term crippling disease. When crippling arthritis strikes, the psychological and sociological stresses that twist and tear at the patient and at all who must suffer with him are so great, both in magnitude and in duration, that they defy quantitative measurement.

The battle that the crippled arthritic must wage to maintain his levels of reserve and adaptability against the onslaught of his disease has profound meaning for all responsible members of society.

Something Can Be Done. The principal problem in preventing disability from arthritis is that of decreasing the interval of time between the patient's first symptoms and the initiation of comprehensive treatment and care. Decreasing this interval is, in part, a matter of patient and public education. Delay in seeking proper care speeds crippling; the informed patient will not delay.

Of perhaps more significance, however, is the related problem of making the patient's first medical contact more effective in leading him to prompt and adequate care. This involves the basic training of the physician and the postgraduate efforts that must be made if the practicing physician is to be kept up-to-date in the field of arthritis. Also, it implies the availability of resources for early and accurate diagnosis and the adequacy of facilities that will provide total or comprehensive medical care that is adapted to the needs of the individual patient.

Unfortunately, public education activities, professional training programs, diagnostic resources, and adequate care facilities are, at present, insufficient. This must change. Something *can* be done for the arthritic. It can be done *now*, if society is willing to undertake the task.

In the prevention of disability from arthritis, there is one fact that has been repeatedly demonstrated; there is one point on which virtually all workers in the field agree: The *early* initiation of comprehensive treatment and care activities, including hospitalization, when necessary, and embodying subsequent and continuing medical and social support, is essential to the prevention of disability from arthritis.

Severe crippling can be prevented. In seven out of ten cases, victims of rheumatoid arthritis can be kept out of the bed or wheelchair. They can be helped to lead a useful and productive life. For this reason, it is of vital importance that community resources be augmented substantially and that they be brought to bear early in the course of the disease, rather than later, as is too often the case at the present time.

Chronic Cripplers Excluded. For too long, the public, professional health workers, and statesmen have been concerned with diseases that kill, to the exclusion of the chronic crippling diseases. As a result, much progress needs to be made. The excellence of current, short-term, inpatient, acute-problem studies has not been duplicated in outpatient work with chronic diseases. Clinical work and planning, which could include a comprehensive program of patient education, is inadequate at many of our better medical schools. Facilities for early hospitalization for patients who would benefit from such care are frequently inadequate. There are too few comprehensive care programs, which could serve as models of educational training of medical students, physicians, and other professional personnel, too few clinics, too few general hospitals, nursing homes, and home care programs, which are capable of dealing with the specific needs of the arthritic, and too few interested health professionals.

With respect to professional education, recruitment, support, and training of both medical and allied health professionals is inadequate. The sparse or nonexistent

training in rheumatic diseases in the curricula of schools for associated professional personnel or in the postgraduate education that is offered to these personnel contributes, substantially, to the present desperate shortage of physical therapists and to the scarcity of other health workers—all of whom should be instrumental in providing optimal care and education for arthritics. In the training of physicians, the orientation of medical undergraduate experience is toward acute, rather than chronic, illness.

Needs Are Great. The prevention of disability and the restoration and maintenance of function require the long-term services of an expensive team of specialists. The facilities that such a team requires are proportionately costly, and they range across a broad spectrum—from acute care beds in a hospital to special devices in a patient's home.

There is much to be learned about this complex and costly disease, arthritis. If new knowledge is to be developed and disseminated, postgraduate training for physicians who are already in practice is imperative. Associated professional personnel must be increased in number and

better trained to deal with the problem of crippling arthritis. And medical students must be exposed to the challenge of this provocative disease.

In addition, the victim of arthritis, his family, and the general public must be set free of the notion that nothing can be done about this disease.

Fundamental research must be continued, but a comparable effort must be mounted in the clinical area. Exemplary care centers should be supported as the focus of study, teaching, and consultation.

And, of particular importance, the community must be helped to organize and to support facilities that will provide a full range of services to the chronically ill, including the arthritic. Everyone who is concerned with health care must be imbued with the philosophy of a team effort, of a persistent and concerted attack, which will not falter in the face of discouragement or disappointment. It must not be forgotten that the needs of millions of Americans will be met only if society decides to redirect its investment, to mold public and private resources into a force that will halt the crippling of arthritis and its impact on the Nation.

Recommendations

1. That the Surgeon General designate arthritis a major health threat that must be surmounted.

Arthritis is the foremostcrippler in the United States. Its impact on the citizens of this country is staggering. Though rarely fatal, arthritis far exceeds the killer diseases in terms of human suffering, misery, and privation. In addition, it imposes on the economy the burden of providing for citizens who have been permitted to become crippled and unproductive. In our society, this burden is accepted. However, since the immense costs of arthritis to the Nation can be prevented, further squandering of these human resources is neither economically nor morally justified. Arthritis is a major threat to the health of the citizens of the United States. As such, it warrants a concerted effort to overcome it by all available means.



2. That facilities for the diagnosis and treatment of arthritis be maintained, improved, and created according to geographic, population, and community needs.

It has been shown that the early initiation of comprehensive treatment and care activities is essential to the prevention of disability from arthritis. As was pointed out earlier in this report, however, diagnostic and treatment facilities for arthritis do not meet today's needs.

The optimal care of chronic arthritic patients requires the combined capabilities of a team of skilled health professionals. The patient's family physician is a most important member of this team, since it is he who is charged with the key role in management. If optimal care is to be provided on an effective and widespread basis, without interfering with the traditional doctor-patient relationship, facilities and personnel for early diagnosis and comprehensive treatment should be established and supported at four basic levels: Re-

gional Arthritis Centers; Diagnostic and Treatment Clinics; Roving Consultation Boards; and an Arthritis Advisory Committee of the Rheumatism Section of The Arthritis Foundation (formerly, American Rheumatism Association).

Regional Arthritis Centers should be university-based or affiliated with large medical centers. They should provide facilities for the diagnosis and exemplary, comprehensive care of outpatients, by both full-time and part-time medical and associated professional personnel, and each Center should contain a limited number of beds for short-term inpatient care. In addition, each Center should operate an automated multi-test laboratory and make laboratory services available to other diagnostic facilities and to physicians in the area. Such laboratories would provide for quality-controlled uniformity and standardization of diagnostic tests—services that are not presently available.

Diagnostic and Treatment Clinics should be established in existing arthritis centers and service clinics and in accredited hospitals or other qualified medical facilities. These clinics would provide facilities for the diagnosis and comprehensive treatment

of outpatients from a defined geographic area. They would be staffed by part-time medical and associated personnel, and policies of financing and admitting would be identical to those of the parent institutions, the Regional Arthritis Centers.

Roving Consultation Boards would make periodic visits to hospitals in communities in which arthritis consultation services are not available. These Boards would be composed of professional personnel from the region's Arthritis Center or nearby Diagnostic and Treatment Clinic.

An *Arthritis Advisory Committee* of the Rheumatism Section of The Arthritis Foundation would be responsible for establishing standards of quality and of procedure for quality control of Regional Arthritis Centers, their automated multi-test laboratories, the Diagnostic and Treatment Clinics, and the Roving Consultation Boards. The Committee would work closely with the U. S. Public Health Service, all other public and voluntary health agencies, and with the American Medical Association.

The philosophy of providing these facilities for early diagnosis and comprehensive treatment should be one of building on the strengths and eliminating the weak-

nesses of present resources, rather than of creating a new structure. Maximum utilization of and sustained support for currently available facilities, together with the creation of new facilities, where needed, will give local physicians easy access to new information, as it becomes available; provide a mechanism for early diagnosis and treatment at the grass-roots level; and provide for the standardization of laboratory criteria for diagnosis. Responsibility for achieving and maintaining a high standard of medical care will rest with the patient's family physician, leading rheumatologists, and the Arthritis Advisory Committee.

3. That recruitment programs and undergraduate, graduate, and continuing education programs for the physician and for associated health personnel be improved and expanded in the area of the rheumatic diseases.

Meeting the needs of the patient with arthritis begins with the recruitment and education of those who will care for and manage the patient. Proper management of arthritis patients can be provided only by persons who have professional knowledge, technical skills, and a commitment to the provision of optimal care and to the development and dissemination of knowledge. Professional people who fit this description—who can meet the ever-increasing demands for patient care, education, and research in chronic illness—are in extremely short supply.

It is precisely because special and supporting skills are not available in quantities sufficient to provide optimal care for the arthritic that there is an urgent need for support of education in these fields, coupled with intensive and imaginative recruiting programs. Because recruiting success is, in the end, largely dependent upon the excellence of educational and training programs, the great need is for programs with the kind of built-in appeal that attracts medical students, well-trained physicians, and associated professional personnel. For this reason, exemplary, comprehensive care centers should be established in conjunc-

tion with medical schools. These centers would be multi-categorically oriented, but would focus on arthritis as a prototype of chronic disease. They would serve as educational facilities in which physicians would work in concert with associated professional personnel and would provide graduate education for all fields. Federal grants to medical schools should be offered to assist in planning facilities and curricula, as well as for the support of faculty. Assistance is also required for the support of large-scale, cooperative studies among all or most of the arthritis teaching centers and study units in the country.

4. That training for and support of better clinical investigation be encouraged by all available means.

The current approach to clinical investigation has produced an abundant and diversified body of knowledge in recent years. For a variety of reasons, however, the emphasis has been on studies of bio-

chemical, immunologic, and morphologic aspects of the disease. Support for these studies has been, and should continue to be, available. In the long run, they are of the utmost significance. Nevertheless, there has been a tendency for these efforts to overshadow fundamental clinical studies, to preempt the attention of investigators, and, thus, to inhibit work that is more directly applicable to patient needs and to the prevention of disability. The detailed recommendations that follow serve to identify means by which this imbalance in attack may be corrected.

It is recommended that support for the Research Training Grant Program be expanded, thus accelerating the training of teachers and clinicians who are primarily concerned with patient care as a research and teaching activity. Physicians who are capable of asking the pertinent clinical questions, of designing studies that are capable of answering such questions, and of carrying these studies through to completion are in short supply. There has been too little emphasis on the kind of excellent clinical judgment and critique that is mandatory in such work.

It is further recommended that clear and

forthright support be made available to clinicians of proven capacity who are in a position to give and to teach excellent patient care and to conduct clinical investigation. Support has been inadequate for the physician whose area of major contribution is in such clinical spheres as defining natural history of disease and establishing the role of a given therapeutic modality. It must be recognized that these problem areas are of fundamental importance, that they are distinctly worthy parts of the total investigational effort, and that, as such, they are areas in which competent, research-oriented clinicians should be supported.

It is recommended that support for hospital beds for clinical investigation be provided within the framework of the arthritis center concept. Hospitalization is of major, yet poorly defined, significance in the management of crippling arthritis. Proper clinical studies cannot be performed without an adequate supply of hospital beds that are available to the subjects. The cost of providing such facilities is more than justified by the fact that each bed serves not one, but three interlocking purposes—exemplary patient care, the teaching of

exemplary care to learners in all professional health fields, and clinical investigation.

It is recommended that research grant applications that pertain, in large degree, to clinical studies be evaluated on a competitive basis with similar studies, rather than with programs that are based primarily in the experimental laboratory. Clinical studies are generally considered to be much more difficult to evaluate than experimentally induced results because of the extended observation programs that are required, the many subjective factors that impinge on the observer, and the slower evolution of scientific truths from observed data. Despite these problems, value judgments can be made if clinical studies are compared only to each other.

There is a great need for a central coordinating agency that would be concerned exclusively with the clinical and epidemiological features of arthritis. Such an agency would provide continuing consultation in the areas of experimental design, biometrics, and data processing. It would serve as a focal point for drawing together widely separated investigators, who might then elect to join others in cooperative studies. And it would be expected to origi-

nate investigative efforts of its own.

Finally, it is recommended that an arthritis research coordinating agency be established as a function of the U.S. Public Health Service. This agency would, on a voluntary basis, contribute to the design and execution of cooperative clinical studies, provide technical consultation in experimental design and biometrics, and assist in efforts to standardize criteria and laboratory procedures. In general, it would coordinate clinical research activities in three major problem areas: 1) The natural history of the diseases and the effect upon them of therapy or lack of therapy, including analysis of such areas as patient motivation and the useful patterns of various agencies, such as centers, clinics, and hospitals; 2) The study of diagnostic criteria, therapeutic efficacy, and such patterns as remission and exacerbation, including both laboratory and clinical features; and 3) Classical epidemiological work, both in terms of measuring the extent of the problem in various areas and under various circumstances and in terms of identifying etiological factors.

5. That all agencies that are concerned with crippling arthritis dramatically improve and expand programs of public education and information.

Comprehensive programs of public education and information are essential to the effective control of crippling arthritis. An uninformed patient and general public can neither intelligently seek good care nor demand that health authorities provide proper treatment and care facilities for arthritis. In lieu of professional help, the victims of arthritis spend \$250 million annually on worthless and fraudulent treatments for arthritis. Obviously, neglect of this disease problem, on all fronts, has created, and is, in turn, caused by, a composite of apathy, ignorance, and misunderstanding. Breaking this frustrating chain of hopelessness will require intelligent and aggressive action by a number of agencies, at a variety of levels.

A public education and information program on arthritis should work to achieve the following goals: To motivate arthritics

to seek qualified care, to seek it sooner than they might otherwise, and to stick with it; to improve the attitude of the public toward arthritis and the attitude of the arthritic toward his disease; to motivate those who produce and disseminate health information to place more emphasis on arthritis; to create in the public an awareness of the size and seriousness of the arthritis problem; and to stimulate widespread interest in a major effort to meet the challenge that the problem of crippling arthritis poses.

If these objectives are to be accomplished, all agencies that are concerned with arthritis must concentrate their efforts in a continuing, nationwide program of information dissemination that will make maximum use of all the tools of communication to inform and educate the general and special publics about arthritis. In years past, the role of the Federal Government in focusing public attention on, and in providing support for, the amelioration of crippling from arthritis has been small. It is now time for the U.S. Public Health Service to provide the resources and leadership that will enable public, private, and voluntary agencies to work together to establish a program of arthritis education

and information that will deal systematically, thoroughly, and realistically with the needs of the millions of arthritics in this country.

6. That a substantial portion of Federal grants for the chronically ill and aged be earmarked for comprehensive community service programs for the arthritic.

The chronic nature of arthritis often requires that programs of supervision and care be continued for a prolonged period of time after the patient returns from the hospital to his home. Basically, two types of supervision are required: Home care programs, for the patient who is still home-bound; and outpatient care programs, for the patient who can leave home. Although necessarily different, both approaches to patient care depend for their success on the availability of a variety of facilities and skills. The availability of these skills and facilities is, in turn, directly dependent upon the support that is given to communi-

ties to plan and to operate comprehensive service programs.

The ultimate aim of treatment of the arthritic patient is to enable him to engage in productive activity in his home and in the community. Because of the tremendous variations in the prevalence of illness and in the resources that a community might have to combat the social, emotional, and economic, as well as the medical, problems of chronic illness, each community must develop the patterns by which it may use its particular resources to the fullest.

It is while communities are developing patterns of resources utilization that they should give serious consideration to the desirability of combining programs for the long-term management of arthritic patients with those that are designed to cope with other chronic diseases. Combined efforts are usually more effective and more feasible than separate attacks on different disorders; and they enhance the management of the arthritic patient without unduly increasing the economic burden on a small community.

Community planning should include provision of facilities for all types of care; the development of appliances and equipment and the training of the patient and his family to use them; the means of bringing together, most effectively, the patient, per-

sonnel, and facilities; and the development of recreational and social activities that can be operated in conjunction with those that are enjoyed by other members of the community. Programs should also include means of evaluating their strengths and weaknesses, in order that they may be modified and improved on the basis of experience.

The need is great for community services that go beyond the hospital and the clinic—that enable the arthritic patient to lead a satisfying and productive life. Federal formula and project grants that are earmarked for arthritis would, if provided, stimulate States and communities to come to grips with the problem of planning for and providing the long-term care that is needed to prevent crippling arthritis.

Background Papers

Workshop 1

Public Education and Information

William S. Clark, M.D., Chairman

It is to be hoped that we have just about reached that stage of civilization when we can say: "Our society can no longer afford the crippling diseases, the most notorious of which is arthritis."

As distinct from the killer diseases, on behalf of which a dramatic mobilization of resources has enlisted overwhelming public response and cooperation, the general attitude toward this most familiar of the crippling diseases has become one of apathy. Perhaps because some form of arthritis has been known as far back in the history of man as we can go, and perhaps

because a habit of frustration has been built up through the years (by the medical profession and by the lay public), this attitude seems to be based on a belief not dissimilar to that held until very recently about poverty: that "rheumatism, like the poor, has always been with us." The built-in implication, of course, is that it always will be and that there's not much point in doing anything about it.

But today, we are taking a new look at poverty in the midst of abundance, and we are attempting to apply intelligent and intensive effort towards its elimination. It would seem to be more than about time to take a new look at the country's leading crippler. This necessarily includes an examination of what can be done to clear away the mists of apathy, now lying like some vast primordial miasma between us and the prospect of successful subjugation of this crippler of mankind. Let us first look at the facts.

Arthritis, the second most prevalent chronic disease, affects an estimated 13,000,000 persons in the United States—one out of every 15 people—and adds 250,000 new victims each year. Over 3,300,000 persons are limited in their activities by arthritis, of which number 697,-



000 are unable to work, keep house, or go to school. Of the 915,000 persons who are confined to their homes by chronic diseases, 17 percent attribute their problem to arthritis and rheumatism. Sixteen percent of over 16,000,000 individuals who are classified as having limitation of major activity report arthritis as the responsible cause.

Arthritis and rheumatism cause 1,223,000 persons to be confined to bed for one or more days each year.

According to the National Health Survey, arthritis caused the loss of 12,000,000 days from work in a recent single year. Arthritis is estimated to cost the Nation approximately \$2,000,000,000 a year, including \$500,000,000 in productivity loss and \$130,000,000 in disability benefits.

When arthritis strikes, there is a double loss: a worker ceases to produce at top capacity, perhaps to produce at all, with all that that means in loss of productivity to the economy, as a whole, and in terms of tax dollars for city, State, and Federal governments. In fact, only too often the wage earner is moved from the plus side of the ledger to the debit side; he becomes a consumer of tax monies.

Proportionately, the arthritides constitute the most neglected group of diseases in the modern approach to good health. The general public has demonstrated no great concern. Funds from private and tax-supported resources that are allocated for research support that is directly related to arthritis are something less than \$15,000,000. Facilities that are provided by the public for diagnosis, treatment, and rehabilitation are generally inadequate or lacking. Of the Nation's medical schools and teaching hospitals, less than one-third have noteworthy programs and projects for treatment, teaching, and research. Fewer than 1,600 physicians in the United States manifest an active interest in the arthritis problem, and it is estimated that there are fewer than 500 properly qualified medical specialists in the field of rheumatology.

We have an ironic situation. On the one hand, there are not enough adequate facilities and not enough professional competence to meet the need; on the other hand, \$250,000,000 a year is spent on worthless and fraudulent treatments. We have a situation in which, even when adequate professional help exists, large numbers of pa-

tients do not seek or avail themselves of good care on the assumption that nothing can be done about arthritis—that it's a hair shirt they just have to live with. Reinforcement of this traditional point of view, driven home by families, friends, and even physicians, is probably deepened by incessant, day-in-and-day-out TV commercials: "Medical authorities state there is *no cure* for arthritis; take aspirin to relieve the pain." Yet, it is now true that, with early diagnosis and comprehensive care, 75 percent of the crippling that is incident to arthritis can be prevented.

It becomes obvious that the neglect of the arthritis problem is due to an amalgam of apathy, ignorance, and misunderstanding. Any solution must include intelligent and aggressive programs, by a number of agencies, at a variety of levels.

Greater public awareness of the nature and magnitude of the problems of arthritis and rheumatism should have the following purposes:

1. To motivate patients to seek qualified medical services and to seek them sooner, so that they will receive earlier treatment and more effective prevention of disability.

2. To improve attitudes toward those that are afflicted, including those in the family, employees, teachers, neighbors, schoolmates, and friends, by encouraging them to replace a fatalistic attitude of gloom with a constructive and hopeful outlook.
3. To motivate large numbers of practicing physicians to become more knowledgeable and more skillful in the field of rheumatology.
4. To motivate more educators to provide, at all levels, more effective and more attractive programs for continuing education.
5. To motivate more hospitals and related agencies to provide optional facilities and resources, as required by knowledgeable physicians.
6. To encourage paramedical personnel to acquire increasing awareness and to improve general skills, knowledge, and services. Paramedical educators will, of necessity, improve programs for undergraduate and postgraduate education.
7. To provide for medical students, interns, and residents greater exposure to the diseases and to motivate them to take greater interest, with the result

that more young persons will seek research and clinical careers in rheumatology.

8. To make more funds available for clinical and basic research.
9. To stimulate the development of new and more effective treatment methods.

Impressing the public with the nature and importance of an insidious and undramatic chronic disease, such as arthritis, is a challenge to physicians, health educators, and specialists in communication techniques.

The successful methods that are applicable to acute and limited morbidity and to the dreaded fatal diseases are not likely to be as effective in public education programs that involve less dramatic, long-term chronic diseases. The problem is further complicated by the need for correcting false and misleading concepts, which are held by vast segments of the public.

New and imaginative methods, involving the development of educational content and of communication, must be devised. Crash programs must be launched. Dedicated representatives from the fields of medicine, health education, and the communications professions must develop

and apply techniques that will get the message across—that will compete favorably with public information programs in other fields.

A new attitude toward health information must be cultivated in editors, newscasters, and writers in the years ahead. Moreover, the effort of government and voluntary agencies must be stepped up to achieve a greater impact. The combined public education activities of agencies should be focused on an immediate goal, the amelioration of crippling.

A critical appraisal of public education by all who play a responsible role is long overdue. Such a review should take inventory of the past and current efforts. On the basis of current and future needs and trends in health education and mass communication, a program must be designed that will deal systematically, thoroughly, and realistically with the problem.

Workshop 2

Diagnosis and Treatment Facilities

Ephraim P. Engleman, M.D., Chairman

The objectives of our Workshop will be:
(a) To consider those community-oriented facilities that are needed for the diagnosis and short-term treatment of arthritis; and
(b) to explore the resources that are potentially available for such facilities.

It is appropriate, at this time, to define the term "arthritis," as it will be used in our Workshop. For purposes of our discussion, the term "arthritis" will be used in a general sense to refer to a group of articular and para-articular diseases, often chronic that cause painful disability, which may be evanescent, episodic, static, or progressive. Examples of such diseases are gout and bursitis, in which the disability may be evanescent or episodic, degenerative joint disease (osteoarthritis), in which disability may be static, and rheumatoid arthritis, in which disability is often progressive.

There are certain problems that must be recognized prior to our discussion of facilities for diagnosis and treatment of arthritis. In the first place, we have little or no information about the cause or prevention of these diseases. Secondly, there is no unequivocal diagnostic test. And of those tests that are commonly used, there are at least two sets of diagnostic tests for which there is no uniformity or standardization. I refer, specifically, to the tests for the rheumatoid and lupus factors and to the criteria for radiologic diagnosis. Thus, our methods for diagnosis are traditional. They include the time-consuming history and physical examination and the performance of laboratory tests and X-ray studies.

A third problem concerns the lack of a cure. Thus, in most instances, we employ several therapeutic modalities, which may be used simultaneously. Examples of such modalities are rest and exercise, in proper balance, and drugs and simple orthopedic supports or appliances. Often the treatment is palliative. Nevertheless, the proper management of early disease will usually reduce pain, preserve function, and prevent progressive deformity. Furthermore, proper treatment will minimize the likelihood of iatrogenic disease.

Some 13 million people in the United States maintain that they have some form of arthritis. This prevalence is so high that responsibility for these patients must be assumed by their local physicians, by doctors with varying interests, including those in general practice. This brings us to the fourth problem, namely, the shortage of physicians with at least a modest degree of skill, or even interest, in the care of the arthritic patient. The gap that exists between the knowledge that is available about arthritis and its application to the patient can only result in a critical delay in accurate diagnosis and proper treatment.

At the community level, we are faced with a fifth major problem: the shortage of arthritis clinics. Although there are approximately seven thousand accredited hospitals in the United States, there are only 300 arthritis clinics, many of which are poorly staffed and equipped. And most of these clinics are restricted to large population centers.

Finally, it must be noted that there is an almost complete absence of certain arthritis facilities that are available in many other parts of the world. Thus, we have, in the United States, virtually no provision for rural arthritis services, hospital beds for arthritis, national registry of patients with

arthritis, a directory of diagnostic and treatment facilities that *are* available, and/or an assessment of screening techniques, which might provide early diagnosis on a large-scale basis.

This, briefly, is the current status of the diagnosis and treatment of arthritis in the United States. That there are vital needs is self-evident. Nearly one-half of the patients who have arthritis are receiving no medical care. Thus, they are candidates for crippling or disability, which might be prevented or minimized. Our Workshop will make practical recommendations, which, hopefully, will satisfy some of our needs.

Workshop 3

The Long-Term Care of Patients with Arthritic Disabilities

Currier McEwen, M.D., Chairman

A. Who are the patients with whom we are concerned?

It is assumed that arthritic patients in acute and severe subacute stages need general hospital facilities and that this Workshop is concerned with those who have progressed beyond those stages. These patients have need of less complex facilities, but, nevertheless, specialized skills and programs.

The patients who are in need of this care include:

1. Those with inflammatory types of arthritis, in mild subacute and chronic stages, without deformities, but whose illnesses can be expected to remain active for many weeks or months;
2. Those with similar arthritis who have

developed deformities that probably can be corrected with nonsurgical measures;

3. Similar patients with advanced deformities, which require surgical measures for correction;

4. Patients with advanced deformities and disabilities, which have little promise for more than very limited correction;

5. Patients with osteoarthritis of the disabling type, who require intensive programs of physical therapy and therapeutic exercises;

6. Similar patients who require surgical measures;

7. Patients with arthritic disabilities, who have little potential for rehabilitation because of other handicaps, such as senility, stroke, etc.;

8. Patients who should be removed from their home environments for short periods, either for intensive supervision of corrective measures or for psycho-social reasons;

9. Patients who are in need of learning Aids to Daily Living;

10. Patients who require prevention of deformity, as well as correction.

These groups include patients of all financial levels, but the needs are especially important for those in low and moderate income groups.

B. Where do these patients now receive care?

Information that is currently available permits only general answers to this question.

The great majority of these patients now receive very inadequate care, either in their own homes, in general hospitals, in chronic disease hospitals, or in nursing homes.

It is probably true that, in many instances, even well-to-do patients, in their own homes, receive inadequate care because of lack of (a) suitable programs, (b) skilled personnel, (c) knowledge of available community resources, and (d) coordination of existing community resources.

C. What are the special needs?

The special needs of the various types of patients who are listed under section A include:

1. Facilities of the simple hospital type with which they can be effectively and economically cared for;
2. Skilled consultant services, provided on a team basis, to plan and periodically assess each patient's program;
3. Ready access to general hospital beds for those patients whose course of disease demands that level of care, because of

intercurrent illness, exacerbation of disease, or suitability for a definitive surgical or other therapeutic measure;

4. Financial arrangements that will permit patients of all economic levels to receive optimal care for whatever period is required;

5. Means of continuing supervision of the program after the patient returns home; and means of providing for his total needs, including care of all illnesses other than the arthritis;

6. Arrangements to facilitate the retraining of patients for jobs that are within their capabilities and assistance in job placement;

7. Development of arrangements to meet the ultimate needs of those patients who have no homes and whose potential for rehabilitation is small.

D. What skills are needed?

The essential skills include those of the:

1. Rheumatologist; 2. Orthopedist; 3. Psychiatrist; 4. Physical Therapist; 5. Occupational Therapist; 6. Psychologist;
7. Social Worker; 8. Vocational Counselor; 9. Nurse and Aide; 10. Public Health Nurse (including Visiting Nurses).

E. What facilities are needed?

These include:

1. Facilities of a simple physical type, which provide a pleasant atmosphere, beds, medical supervision, nursing care, space and equipment for therapeutic exercises, splinting and other unelaborate measures, and facilities for recreation, where constructive rehabilitation programs can be most effectively and economically carried out for patients of the types that were noted under section A;
2. General hospital beds, to which patients can be transferred readily if their medical needs demand it;
3. Consideration must be given to the roles of existing types of facilities, such as nursing homes, in the care of these patients;
4. The patient's own home should be the most important facility of all in the ultimate care of the arthritic. Means must be developed to make the home an effective place for the continuation of constructive programs;
5. Development of more shops with facilities for the employment of rehabilitated arthritic patients.

Workshop 4

Professional Education

Howard F. Polley, M.D., Chairman

Increasing attention is being given to arthritic diseases, not only because they are conditions for which satisfactory scientific answers have not yet been found, but also because of the increasing awareness of the associated public health and community problems. No doubt, both scientific and public interests have been stimulated by research efforts, especially those of the last 15 years or so, that have been directed toward the solution of both the clinical and the basic science aspects of the biochemical, cellular, and other abnormalities that occur in various arthritic diseases. Although interest in arthritis prompted such investigations, the resulting scientific and public health benefits may extend to areas far beyond those of the diseases toward which the efforts were initially directed.

The increasing attention that arthritis

has received has also revealed major obstacles to the solution of community health problems that arthritic diseases present. The recognition that there are such obstacles and that they may not yet have been defined well enough to facilitate their solution is the basis for this conference, which has been called by the Surgeon General, U.S. Public Health Service. Our Workshop's attention is particularly directed to the professional education aspects of the prevention of disability from arthritis.

Obstacles that are related to the professional education aspects of better public health management of arthritis may include: (1) shortages of skilled professional personnel in various pertinent medical and paramedical fields; (2) inadequate use of presently available knowledge and public health techniques to determine which persons and which areas would be amenable to preventive measures; (3) public and professional indifference to the ever-increasing magnitude of the social and economic consequences of failure to prevent disability; and (4) financial requirements of the correction of recognized deficiencies.

In order to obtain a better approach to the solution of these obstacles and of those that are, possibly, less well recognized, it

seems necessary to define, more clearly, the current resources, such as the number of presently available medical and paramedical specialists, whose skills could contribute to the prevention of disability in areas in which they are now located. It seems necessary, in addition, to determine how they function in their medical and social communities. A whole series of corollary questions that are suggested are listed below.

How can the talents of these specialists best be used?

What are the optimal methods of teaching and training medical and paramedical skills at the professional level?

How can professional education attract the dedicated interest of knowledgeable graduate physicians and scientists and paramedical personnel, such as physical and occupational therapists, social-service workers, nurses, nutritionists, and others, for prevention of disability?

What are the relationships, if any, between the undergraduate educational experiences in either clinical or research aspects of rheumatic diseases and graduate professional education?

Who can undertake professional education most effectively, and where?